

VIRGINIA BLEEDING DISORDERS PROGRAM

What is the Virginia Bleeding Disorders Program?

The Virginia Bleeding Disorders Program (VBDP) is a program established by the Commonwealth of Virginia through the Virginia Department of Health, Office of Family Health Services, Children with Special Health Care Needs Program. The VBDP promotes the care and treatment of persons with hemophilia and other congenital bleeding disorders. Virginia recognizes that the ongoing medical costs of treating such bleeding disorders often exceed the financial capacity of families, despite the existence of various types of medical and hospital insurance.

The VBDP provides a "safety net" for persons with congenital bleeding disorders. The program recognizes the importance of comprehensive bleeding disorders care and the need for hospitalization and frequent outpatient or home therapy in order to promote the health of persons with hemophilia and related diseases. Therefore, the Program seeks to provide coordinated, family-oriented, multidisciplinary services for persons with congenital bleeding disorders.

Who can participate in the VBDP?

Any resident of Virginia with Hemophilia A, Hemophilia B or von Willebrand Disease may apply for the Program, regardless of income.

What are some of the benefits of the VBDP?

The VBDP was established out of requests by parents and families to the Virginia General Assembly to assist them in providing quality, affordable care for their relatives with inherited bleeding disorders.

First of all, the VBDP acts as a "safety net" for persons with hemophilia or von Willebrand Disease. Almost 20% of persons with insurance change policies each year. This could be related to divorce, job changes, temporary unemployment or the increased cost of premiums. Also many employers change the coverage of their health care plans with or without employee input. During such transitions, many families have found that comprehensive care and/or factor concentrates were no longer entirely covered. Others have changed policies only to find a preexisting condition on hemophilia care and factor concentrate. Given the expensive nature of hemophilia care, such costs can be overwhelming. Moreover, some families are not aware of their options in maintaining health insurance during such transitions. The VBDP assists persons with bleeding disorders in considering their insurance options.

Secondly, the VBDP helps sponsor the bleeding disorders clinic. This support includes certain team member time, vaccinations for hepatitis A and B, and assistance in the coordination of care. The program coordinator may act as the nursing

case manager for persons on the State Program. At the Richmond Hemophilia Treatment Center, the program coordinator serves as the primary nurse coordinator. In other areas of the state, the coordinator collaborates with the bleeding disorders treatment center nurse coordinator, especially in planning home infusion training, acting as a liaison on health insurance and home care issues, and addressing statewide needs of the program.

Thirdly, the program coordinator also staffs the Virginia Hemophilia Advisory Board. This board, appointed by the governor of Virginia, advises the Virginia Board of Health in issues related to inherited bleeding disorders. The Hemophilia Advisory Board provides a mechanism to address the statewide needs of persons with inherited bleeding disorders

What does enrollment in the VBDP mean for me? What are the two levels of enrollment?

As of July 1, 1998, the VBDP Bleeding Disorders Program will have two levels of enrollment: **Basic Program Enrollment and Full Program Enrollment** for patients up to and through their twenty-first year of age.

Basic Program Enrollment:

Patients who have some form of third party payer (private insurance, Medicaid or Medicare) are enrolled at this level. Their insurance is their primary payer, and the VBDP serves as a "safety net." For comprehensive clinic visits, the VBDP will be a secondary payer, meaning that the VBDP will be billed for charges greater than what the insurance has paid. No annual fee or spenddown is charged to participate in the program. A CHS-1 is completed and updated annually.

If a patient's insurance requires a "copay" (generally \$10-\$25 per visit for a specialist visit), the patient must pay this fee. If the insurer requires a referral, this must be obtained. As always, any deductibles must be met before insurance or the VBDP will pay for services.

Full Program Enrollment:

Patients in this level do not have a third party payer, such as insurance or Medicaid. The VBDP Bleeding Disorders Program serves as their primary payer for bleeding-related medical care. A family's gross income and size are used to decide if the family needs to meet a spenddown before the program can assist them with medical bills.

At the "Full Program Participation" level, what is the "spenddown?"

Families with gross annual incomes above 200% of the poverty level (233.3% in Northern Virginia) **must meet a 5.0% spenddown before the VBDP can pay for services.** Once the family has incurred or been billed for medical services equaling 5.0% of their gross annual income for medical bills of the program patient(s) during the twelve month period from the date of admission to the program, the VBDP may

assist the family pay for additional bills for VBDP-covered services. These medical bills include office visits to physicians, medications, medical supplies and equipment, dental and orthodontic services, laboratory and x-ray or other imaging tests, surgery or hospitalization that are not paid or not fully paid by health insurance.

Just as many families compile a list of non-reimbursed medical bills for tax purposes, the family records these incurred expenses and, when reaching the 5.0% level, are sent to the program coordinator. Another method of “paying the spenddown” over twelve monthly installments has also been developed for families who may not incur medical bills amounting to the spenddown.

Families are encouraged to discuss with the coordinator how to calculate and report the spenddown. Even families with excellent health insurance should keep such records since unanticipated bills, changes in insurance policies and coverage and other circumstances may unexpectedly result in expensive non-reimbursable medical bills.

What happens if I lose my insurance or Medicaid/Medicare?

The VBDP works very closely with patients and families to try to keep them insured. Sometimes conversion plans or Cobra plans are available to families who are at-risk of losing their insurance. Strict time frames must be followed in applying for these programs. Therefore, prompt phone calls to the bleeding disorders treatment center and the VBDP are extremely important.

If insurance and/or Medicaid/Medicare is

discontinued, patients can “move” from the “Basic Program Enrollment” to the “Full Program Enrollment” by contacting the VBDP Office, completing the necessary paperwork and perhaps paying a fee and spenddown.

What does the VBDP Program cover?

The VBDP covers:

- * comprehensive clinic services provided by a team consisting of a hematologist, nurse coordinator, orthopedist, physical therapist, nutritionist, social worker and geneticist.
- * hospitalization for severe, emergency bleeding episodes; preauthorized hospitalizations related to the bleeding disorder
- * emergency room care for acute bleeding episodes
- * required orthopedic surgery (up to age 21 years)
- * home infusion training
- * physical therapy
- * laboratory tests related to the bleeding disorder
- * factor concentrate and hemophilia-related medications (i.e. Amicar)
- * orthopedic appliances such as splints and casts (up to the age of 21)
- * imaging procedures (x-rays, CAT scans etc) related to diagnosing or monitoring bleeding episodes

What is not covered by the VBDP?

Services not covered include:

- * Dental procedures or factor required for dental procedures.
- * Elective surgery and/or factor concentrate used in elective surgery or rehabilitation from such surgery.
- * Medical care provided out-of-state.
- * Unauthorized, non-emergency hospitalizations
- * HIV-related medications (Some of these medications may be provided to low-income, uninsured persons through other programs. The nurse coordinator can assist with accessing these programs.)
- * Immune tolerance therapy for persons with inhibitors.

What is Medically-Indigent Medicaid & FAMIS? Why does my child have to apply in order to stay on the VBDP?

Medically Indigent Medicaid is a qualifying category of disability that benefits some individuals with hemophilia, especially children under the age of nineteen. Infants and children with family income that meets current Medicaid requirements for coverage are referred to Medicaid for eligibility determination. Such children may receive clinic services while applying for Medicaid, but the Program can not pay for hospitalization or ancillary services until the appropriate Medicaid application has been processed for denial or acceptance. Therefore, the State Program maximizes the use of all available resources to assist children and families.

Family Access to Medical Insurance Security Plan (FAMIS) is a program for uninsured children up to age 19 who do not

qualify for Medicaid and live in families with incomes up to 200% of the Federal Poverty Level. The plan provides comprehensive health care benefits provided through managed care health insurance programs. The Virginia Department of Medical Assistance Services administers the FAMIS program.

FAMIS is not available to children who are inmates in a public institution, are an inpatient in a mental health facility, have access to state employee health insurance, or have had other “credible” health insurance in the past four months. Several “good cause” exceptions for not waiting several months are considered.

Visit the FAMIS website at www.famis.org or call 1-866-87FAMIS for more information.

Who should I contact for more information about the Virginia Bleeding Disorders Program?

The program coordinator may be reached at (804) 827-3306. The office mailing address is:

**Virginia Bleeding Disorders
Program
VCU/MCV Station
P.O. Box 980461
Richmond, VA 23298-0461**

Toll free #: 1-866-228-2516

4/7/04